Newsletter

West London & Middlesex Branch
Summer 2023, Issue 121

motor neurone disease association

Welcome!

Welcome to our Summer Newsletter. We’ve got lots to report.

- We start with an update from Kapish on future plans for Branch meet-ups.
- On pages 3&4 we look back at the recent West London Queer Project 10k Walk and Pride Celebration.
- Other fantastic fundraisers by branch members and supporters are covered in pages 5-9. We also introduce easyfundraising where we can all raise money when we shop online.
- In our Care and Support section (pages 10-13) we introduce new ASC Kathryn Parkin. We summarise upcoming Support Group meeting plans and other ways of receiving support.
- We still need volunteers to get going on Campaigning – see more on page 13.

Jeremy Vine, Zoe Nixon, Ruth Cadbury MP and Aubrey Crawley greeting the walkers

Find us on Facebook

Find the Branch Facebook page by searching for West London and Middlesex MND or via https://www.facebook.com/WestLondonandMiddlesexMND/

Follow us on Twitter @WL_MND

We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

Branch Activities

Kapish Looks Ahead

The committee members and I have been thinking about the best way forward as a Branch in these post-COVID times. I have also spoken to many of you, and your feedback has been invaluable.

Get-togethers

We have all noticed that attendance at the last few Open Meetings has been low. That's why we introduced Monthly Get-togethers, to see if they worked better. The Get-togethers are an opportunity for people living with MND, their families and carers, and other supporters to come together in a very informal setting to share thoughts, ideas and experiences with like-minded people. The emphasis is on 1-2-1 chats rather than formal presentations. We think this format has lots to offer and hope you do too.

Open Meetings

That's not to say we have given up on Open Meetings, although we haven't held any for a while; this is to give the Get-togethers a chance to settle in. We'd still like lots of you to join us once – or maybe twice – a year to enjoy a bigger Branch gathering with food, drink and entertainment. As well as having fun, it's a great way to meet each other in person, welcome new members and plan our future activities. We are looking at an end of year party to be our next such event and we will, of course, keep you posted.

Branch Communications

To reflect these changes, we have altered our communications a bit too. Instead of 4 newsletters a year (falling between the Open Meetings) we are reducing this to a Summer and a Winter edition. To keep track of Get-togethers, Support Group meetings, fundraisers and all other events, we will be sending out more frequent emails. Social media and our website will keep you up to date too.

In making these changes our aim is to create an even stronger Branch community - committed to providing care and support for people living with MND, raising funds, and building awareness. We welcome your support in each of these activities as we fight to find a cure for MND and make life better for those living with it.

We invite your thoughts on all these plans.

Kapish
Kapish Narda, Branch Chair

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Monthly Get-togethers

Here are the details of our monthly Get-togethers.

Date: 2nd Thursday of each month. So, for the next two that's: 10 August, 13 September.
Time: 2-4pm.
Place: The Duke of Kent, Scotch Common, Ealing, W13 8DL.
The Duke of Kent pub has a free car park and there are a few parking spaces in the nearby road. Buses are an option too. The E2, E7, E9 and E10 all go from Ealing Broadway Station to Scotch Common and different onward destinations.
You can find more directions here: www.dukeofkent.co.uk/find-us

A Wonderful Walk


Warming Up for the Walk

Jim Marshall talks about MND

This year, instead of holding our Bushy Park Walk, we were invited to join in the West London Queer Project 10k Walk and Pride Celebration. WLQP generously offered to use the event to raise funds for MND in support of their close friend Zoe Nixon. Zoe is a member of our branch and is living with MND.

Supporters from our branch and WLQP all met up at Furnivall Gardens, Hammersmith W6 on the morning of Saturday 3 June. We were welcomed by the wonderfully entertaining drag queen, Beary Poppins, who led the proceedings and introduced our Branch Patron Jeremy Vine who had come to see us off. Jeremy gave Zoe a big hug, paid her a glowing tribute, and wished us all a wonderful day. Local MP Ruth Cadbury was also there to lend her support. After a brief warm up, just before 1030, we set off on our 10K walk. Zoe had also organised a shorter, accessible walk.

Events Diary Dates

Get-togethers:

Thursday 10 August
Thursday 13 September

Branch is on Instagram
Want to see the branch in action?
Follow us @mndwlandmiddx

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A Wonderful Walk

We crossed over Hammersmith Bridge and followed the towpath to Chiswick Bridge where we crossed back over the river, ending our walk at The Black Lion pub. There were about 200 walkers and everyone was in good spirits, helped by some sunny weather.

Sincere Celebrations

As everyone settled down to enjoy drinks and burgers in the garden, Beary Poppins invited Jim Marshall, Branch member and Trustee and Honorary Treasurer of the MND Association, to speak. Jim thanked WLQP and especially Aubrey Crawley for organising such a great event. He too paid tribute to Zoe and applauded her bravery in making her diagnosis known. Jim spoke about the devastating effect of MND and the essential need to find a cure. Events such as this walk are vital, both to raise funds and awareness.

After these rousing words, Beary then led us through an afternoon of great entertainment from Luna Cortez, Crayola the Queen, Pixie Polite and Miss Lola Lasagne - a wonderful selection of drag queens who truly made our day.

Looking back Zoe say, ‘It was a fantastic day from start to finish. Well done everyone for completing the walk and joining the fun celebrations afterwards. Thanks to Aubrey and everyone who helped with the event - your kindness really does give us strength as a family. We will keep on doing what we can.’

We are pleased to report that the Walk raised more than £2,500 – many thanks to everyone involved.

Great entertainment from Luna Cortez

Contact Us

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Fundraising

In the last few months many of you have been involved in further fundraising efforts. It's fascinating to see all the different ways there are of raising funds. We give the Just Giving pages of each of these events in case there's one you'd particularly like to support.

Zoe Skydives Too

Zoe Nixon's bravery knows no bounds. When Zoe, her daughter Charlie and her sister Lizzy all received Skydives as presents, they decided to use them to raise money for our Branch – in addition to the monies raised by the WLQP Pride Walk in Zoe's honour. Zoe's partner, Levent, has also done a dive.

Zoe's children clearly take after her. As Charlie says: ' My mum has always been fearless, and MND hasn't and will not change that. Her strength empowers me every day to try new things and challenge myself. So, thank you mum for showing me that life is too short to be afraid.'

Zoe, her family and partner have raised over £3,500 with their dives and you can add to that here:
https://www.justgiving.com/page/mndovermatter-123456789

David Young's Marathon Effort

David Young, one of our branch members, was diagnosed with MND in May 2022. Since then, David has become a truly active fundraiser, and took part in the Rob Burrows Leeds Half Marathon on Sunday 14 May. So far, he has already raised a fantastic £10,604 for the MND Association.

As David says on his Just Giving page, 'In my own personal battle, I know MND will win in the end, but not today! While I physically can, I want to pay it forward by raising funds to support the Association in all they do to help sufferers of this cruel disease and their carers.'

You can add your support here:
www.justgiving.com/fundraising/david-young72

Graeme Bloom's Bucket List

In July 2021, after 3 years of ill health, branch member Graeme Bloom was diagnosed with MND. His response was to set a bucket list of things to do leading up to his 40th birthday in July, while raising money for the MND Association. Graeme is a follower of theatre, so he organised a collection after the matinee of 2:22 a Ghost Story at the Lyric Theatre on 22 April. Branch members helped with the collection and together we raised £450.

Graeme meeting the cast

Graeme also takes a keen interest in rugby. He has found different ways to be involved from his wheelchair: doing the Captains Coin Toss, leading the Referee onto the pitch, and blowing the KO, Second Half and Final Whistle. Graeme's fundraising activities will culminate in a rugby match in Bristol on 12 August, followed by a dinner and auction. See more here:
https://www.gofundme.com/f/graemes-big-40-challenge.

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Enterprising Maya Jain

Another member of the Jain family has stepped up to help raise funds. This time it's Maya - Mohit and Lisa Jain's daughter. Maya is in Year 10 at Ealing Fields High School. The school has a system to raise money for charity whereby each form nominates their favoured charity. Maya, whose grandfather Omprakash was lost to MND, suggested the MND Association. This won her form's vote, so they will be raising funds for the Association for the next 5 years.

To raise funds, the form holds an Enterprise Day when they hold a range of fun activities. This year's Enterprise Day was held in March. They had a cake sale and were also allowed to pay to not wear their uniform and to throw a pie at a teacher. All good fun and a great way to raise money.

Well done Maya for thinking about MND and good luck with your future money raising!

A Double Celebration

Ron and Wendy Merritt have recently celebrated 60 years of marriage and both turning 80. Following an MND scare a few years ago, Ron decided to fundraise to help those whose lives MND has affected. They put on a party for all their friends and family at Fulwell Golf Club and held a raffle and auction to raise money. Here's what Ron says about the event:

"Wendy and my gift was being fortunate enough to be able to celebrate reaching 80. It was an opportune occasion to ask our friends and family to donate to the MND Association, instead of bringing a gift. A great time was had by all. I was humbled by the generosity of people in small businesses, that I didn't know, who generously gave raffle prizes. I felt nervous asking at first but was consistently reminded that I was in such a blessed and fortunate position and that the Association is an amazing charity. Providing support for those challenged with the disease has to be a priority, feeling awkward about asking for donations is a small price to pay."

They have already raised a great £3,500+ and you can add to it here.
www.justgiving.com/page/ron-wendy-80

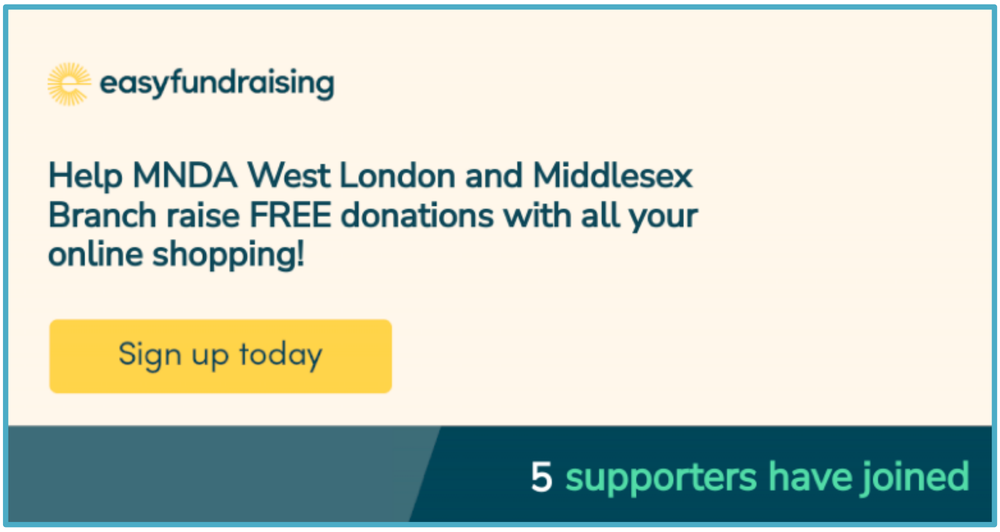
Remembering Lekshmi

Geetha Menon and friends often joined our Bushy Park walk in memory of their friend Lekshmi Krishnan, who passed away in 2014 with MND. This July, Geetha is organising an event for friends and family, with Indian food and dance to raise money for the MND Association. If you'd like to support Geetha's memorial to Lekshmi, here's the JustgivingPage : www.justgiving.com/page/mnda-gm-2023.

Remembering Glyn Roberts

Grace O'Donohoe lives in West London and lost her brother, Glyn Roberts, to MND. On 1 July Grace and 5 other family members and friends walked 17km of the Thames path from Kew to Hampton Court. On the same day, other friends and family climbed the Llanberis path in Snowdon. An excellent effort by all. Here's the JustgivingPage
https://www.justgiving.com/page/roberts-family-and-friends

Charity Begins at Home



Help MNDA West London and Middlesex Branch raise FREE donations with all your online shopping!

5 supporters have joined

Did you know we can all support our Branch by raising money every time we shop online? Your support will mean we can support those living with MND and their families in our area and it doesn't cost you, or us, a penny.

We're using easyfundraising, a free fundraising platform that allows us to earn money when we shop online. easyfundraising works with over 7,400 online brands:

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Charity Begins at Home

from Sainsbury's, SportsDirect, Groupon, The Range, Screwfix, M&S, John Lewis, Booking.com, and everything in between.

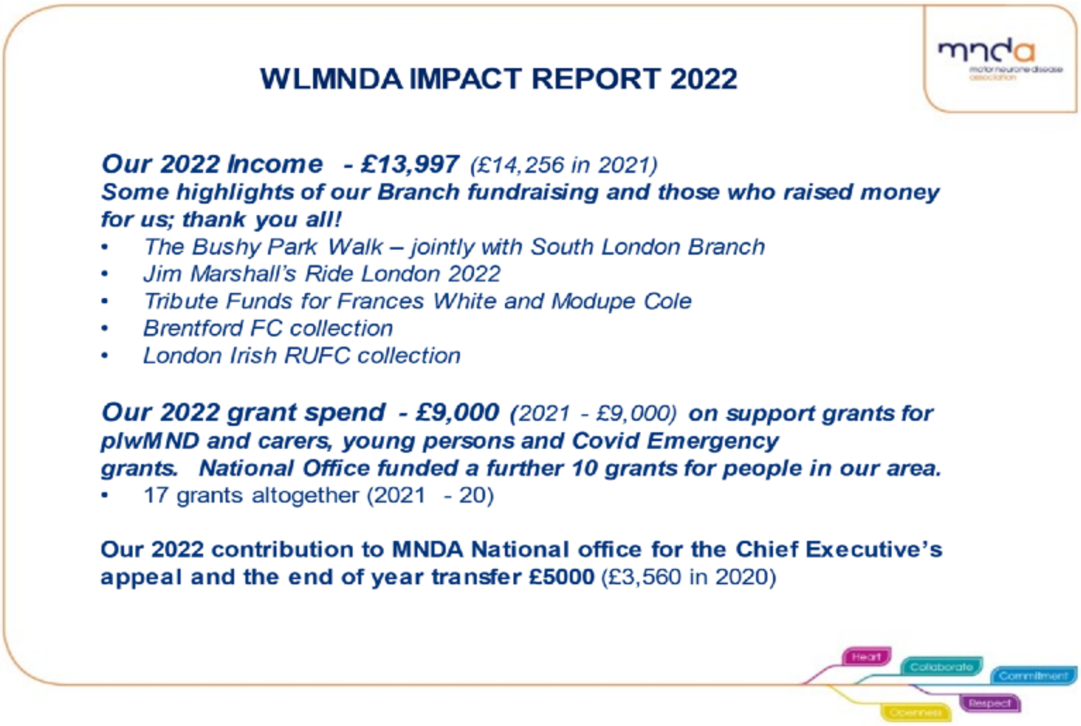
Once signed up, all you need to do is start your shopping journey at the easyfundraising website, use the donation reminder or app (information will be provided when you register) and the brands you shop with will send us a donation based on how much you spend.

With the general cost of living impacting everyone, this isn't about asking you to spend more, but to make you aware that if you are making an on-line purchase anyway, booking travel or taking out insurance, by using easyfundraising, you can give to us at the same time, and at no cost to you.

So please support us today at https://www.easyfundraising.org.uk/causes/mnda-west-london/ It only takes 2 minutes and all you need is your email address. Share with your friends and family too – the more the merrier!

Special Offers

easyfundraising also hold regular special offers where, for a given time, for specific products and services the donation amount is increased and the price you pay is decreased. The special offers often include increased donations when booking a holiday – and that can really make a difference to the amounts raised. Well worth taking a look.



WLMNDA IMPACT REPORT 2022

Our 2022 Income - £13,997 *(£14,256 in 2021)*
Some highlights of our Branch fundraising and those who raised money for us; thank you all!

- *The Bushy Park Walk – jointly with South London Branch*
- *Jim Marshall's Ride London 2022*
- *Tribute Funds for Frances White and Modupe Cole*
- *Brentford FC collection*
- *London Irish RUFC collection*

Our 2022 grant spend - £9,000 *(2021 - £9,000)* ***on support grants for plwMND and carers, young persons and Covid Emergency grants. National Office funded a further 10 grants for people in our area.***

- 17 grants altogether (2021 - 20)

Our 2022 contribution to MNDA National office for the Chief Executive's appeal and the end of year transfer £5000 (£3,560 in 2020)

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Care and Support

Welcome Kathryn!

We'd like to welcome Kathryn Parkin, our new Area Support Coordinator for West London and Surrey, who has recently taken over from Lisa Burnard.

Kathryn brings huge experience to the job. Her background as an Occupational Therapist gives her an in-depth understanding of how Health & Social Care professionals and local Social Services operate. Kathryn has frequently worked with people living with MND and was an Association Visitor for 8 years.

As an ASC, Kathryn works to ensure that people living with and affected by MND are well supported. Alongside informing people about what the MND Association, its local Branches and volunteers offer, this involves creating connections and co-operation between health and social care colleagues, and local community services. Her role extends across 13 very different boroughs, so there's lots to learn and lots to do. Kathryn is very excited by the challenge and is well equipped to deliver. We welcome her and wish her well.

Support Groups

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Support Groups

Here's a reminder of the different groups and the dates of meetings in 2023.

The North, NW & West London Support Group for local people living with MND and their carers. It takes place on the first^t Wednesday of the month at 11am. **Dates**: 2 August, 6 September, 4 October, I November, 6 December. If you have any questions, contact Kathryn.Parkin@mndassociation.org

The Recently Diagnosed Group covers London, Essex, Surrey and Kent. It is for those who want to learn more about living with MND, and each meeting focuses on a separate topic. It provides useful guidance for those navigating the health and social care system for the first time. Meets on the third Friday of the month at 2pm. **Dates**: 18 Aug, 15 Sept, 20 Oct, 17 Nov, 15 Dec. If you have any questions, contact Lisa.Burnard@mndassociation.org

The Online Carers Group is for those who care for people living with MND in London and the South East. Meets on the first Tuesday of every month at 11am and a WhatsApp group adds further opportunities to stay in touch. **Dates**: 1 Aug, 5 Sept, 3 Oct, 7 Nov, 5 Dec. If you have any questions, contact Alli.Anthony@mndassociation.org

The Evening Online Carers Group meets on the last Wednesday of the month at 6.30pm. It's very popular with carers who find it hard to meet up during the day. **Dates**: 26 July, 30 Aug, 27 Sept, 25 Oct, 29 Nov, 20 Dec. If you have any questions, contact Alli.Anthony@mndassociation.org

PMA-PLS Support Group: Progressive muscular atrophy (PMA) and primary lateral sclerosis (PLS) are specific forms of MND, and this group focuses on the particular needs of those living with or affected by the condition. It is an international group. It meets on the second Monday of the month at 5pm (UK time). **Dates**: 14 Aug, 11 Sept,9 Oct, 13 Nov, 11 Dec. If you have any questions, contact Alli.Anthony@mndassociation.org

Here are some new groups you might not have heard of yet:
The Veteran Support Group enables MND veterans to support each other, sharing their experiences and common interests. The first meeting date is Friday 18 August at 3pm. If you have any questions, contact Dawn.Pond@mndassociation.org

The Tracheostomy Group is for carers of plwMND who have had a tracheostomy, to share ideas and experiences. The next meeting is 25 July at 6pm. If you have any questions, contact Lisa.Burnard@mndassociation.org

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Can You Help?

If you enjoy listening to and helping people, are looking for a volunteering role where you can do just that, whilst fitting it around your family, studies, or other commitments, why not consider becoming an Association Visitor or Support Volunteer? By giving your time, energy, and skills you can make a real difference to the lives of people living with and affected by MND.

You can find out more about these and other volunteer roles here: https://www.mndassociation.org/get-involved/volunteering/volunteer-zone/your-volunteer-role

If you have any questions, do contact our ASC, Kathryn Parkin. And if you know anyone who'd like to do some volunteering, and you think this might suit, do encourage them to get in touch.

Requesting Support from the Branch

Our fundraising efforts mean we can offer grants to those who qualify. The support we offer can include funding equipment or services, cost of living support, and improving quality of life. We can also award grants to carers of plwMND and young people living with someone with MND.

What we can fund, and how much we can give, is subject to MND Association guidelines. You can see those here: www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd

Also, do bear in mind that most items of equipment and adaptations require the recommendation of a health or social services professional. Please get this at the outset, not least to make sure it's right for you.

Other than in exceptional circumstances, we do not fund items retrospectively, or which health and social services are required to supply. So, do contact us before incurring any costs.

Many people are under financial pressure at the moment. If you think a grant would help and you qualify, please get in touch with Naomi: naomi.neville@mndassociation.org

MND Association Benefits Advice Service
Find out what benefits you are entitled to and how to claim them
0808 801 0620
www.mndassociation.org/benefitsadvice to send an e-mail or start a web chat

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Broader Support from INS

Plw MND and their carers can also benefit from calling on complementary forms of support and therapies.
INS: Integrated Neurological Services has been operating in West London for over 25 years to support adults with neurological conditions and their carers. Run by Sarah Vines, INS provides therapy, emotional and social support by providing one-to-one therapies and counselling, plus a range of exercise, therapy and creative groups. INS covers Richmond, Hounslow and the surrounding boroughs.

If you'd like to learn more about this excellent service, check out the website here: www.ins.org.uk email admin@ins.org.uk, or telephone 0208 755 4000.

How we can help

Please let us know if you are experiencing any delays or issues with your wheelchair that are affecting your quality of life

We are here to support you and ensure any problems you are facing can be evidenced and addressed as soon as possible.

Please contact Anne Buchanan at:
wheelchairqueries@mndassociation.org or contact her direct on:
01604 611694

Campaigns

We are still looking for volunteers who can take on some specific campaigning tasks. Those who have been involved in campaigning say they find it very rewarding. If you'd like to give it a go, do have a chat with Kapish.

To find out more about the Association's current campaigns take a look here: https://www.mndassociation.org/get-involved/campaigning/take-action/

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MND Connect

MND Connect provides information and support for people living with MND, those affected by MND, carers and health and social care professionals. Whether you have a specific question, or just want someone to listen, the team is here to help.

MND Connect is available Monday to Friday between 9am to 5pm and 7pm to 10:30pm.
Call 0808 802 6262 or email mndconnect@mndassociation.org

Branch Contact

Jenny Gadsby, our Branch Contact, remains ready and waiting to hear from you. Jenny responds to enquiries from people living with MND, their family and friends. She can tell you all about our Branch activities and the local support available, as well as introduce you to the MND Association and the wide range of information and support it provides. You can contact Jenny by email (gadsbyj@hotmail.com) or on the dedicated Branch Contact number: **0787 906 8870.**

Receiving this Newsletter

If you would like to:
- Receive our newsletter and emails on a regular basis (and have not yet subscribed)
- Receive a printed copy of this newsletter by post (if you can’t access it on a device)
- Unsubscribe from this newsletter and emails

Please email Ross: communications@wlmnda.co.uk with your request and giving your full name.

Registered Charity No 294354. Registered address: Motor Neurone Disease Association, PO Box 246, Northampton, NN1 2PR

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